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## Physical Access Barriers to Care for Diagnosis and Treatment of Breast Cancer Among Women with Mobility Impairments

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### Abstract

**Objective**—To explore the perceptions of breast cancer patients with mobility impairments of the physical accessibility of health care equipment and facilities

**Research Approach**—One- to two-hour individual interviews, audiotaped

**Setting**—Interviews in homes or workplaces or by telephone

**Participants**—20 women with chronic mobility impairments who developed early-stage breast cancer before age 60; 3 recruited from oncologist panels and 17 from informal networks of disabled women nationwide

**Methodologic Approach**—Qualitative analyses of interview transcripts to identify common themes

**Main Research Variables**—Extent and nature of mobility impairments; concerns raised by interviewees about barriers to care

**Findings**—The 20 participants identified problems with inaccessible equipment, including mammography machines, examining tables, and weight scales. Sometimes women needed to insist on being transferred to an examining table when physicians preferred to examine them seated in their wheelchairs. When staff would transfer them, patients feared injury; patients felt badly when clinical personnel were injured during transfers. Other problems included difficulties with positioning and handling patients' uncontrollable movements. Even when clinical sites had accessible equipment, this equipment was sometimes unavailable when the woman arrived for her appointment.

**Conclusions**—Women with major mobility problems who developed breast cancer confronted numerous physical barriers during the course of their breast cancer diagnosis and treatment.

**Interpretation**—With the aging of “baby boomers,” increasing numbers of persons seeking health care services will have mobility impairments. Health care providers should plan proactively to accommodate these patients by considering accessibility whenever they acquire new equipment, renovate older structures, or build new facilities. They should also establish policies and procedures to assure that accessible equipment is available during appointments of people who

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need it and that staff are trained in safe transferring procedures. Ensuring accommodations and accessibility will benefit not only patients with impaired mobility but also clinical staff.

Women with disabilities can experience disparities in their health care compared with other women (U.S. Department of Health and Human Services, 2000; U.S. Department of Health and Human Services, 2005). In particular, they are less likely to obtain screening mammography than are other women (Chan et al., 1999; Chevarley, Thierry, Gill, Ryerson, & Nosek, 2006; Iezzoni, McCarthy, Davis, & Siebens, 2000; Iezzoni, McCarthy, Davis, Harris-David, & O'Day, 2001; Iezzoni, 2008; Nosek & Howland, 1997; Wei, Findley, & Sambamoorthi, 2006). Women with disabilities who develop breast cancer may have lower rates of breast conserving surgery (BCS); even if they do undergo BCS, they may receive radiation therapy less often (Iezzoni et al., 2008; McCarthy, Ngo, Roetzheim, Chirikos, Li, Drews, & Iezzoni, 2006b). Women with disabilities are more likely to die from their breast cancers than are other women (Iezzoni et al., 2008; McCarthy, Ngo, Roetzheim, Chirikos, Li, Drews, & Iezzoni, 2006b).

Many factors might explain disparities in screening and BCS rates, including complex medical considerations and women's preferences for care (Iezzoni & O'Day, 2006; Reis, Breslin, Iezzoni, & Kirschner, 2004). Physical access barriers may also contribute to health care disparities for persons with disabilities (Bachman, Vedrani, Drainoni, Tobias, & Maisels, 2006; Drainoni et al., 2006; Iezzoni & O'Day, 2006; Kirschner, Breslin, & Iezzoni, 2007; Liu & Clark, 2008; Mele, Archer, & Pusch, 2005; Reis et al., 2004; U.S. Department of Health and Human Services, 2005). Despite 1990 passage of the Americans with Disabilities Act (ADA) and 2008 passage of the ADA Amendments Act (Thomas & Gostin, 2009), health care facilities often remain physically inaccessible (Iezzoni & O'Day, 2006; Iezzoni, 2008; Kirschner et al., 2007; Reis et al., 2004). A survey of Los Angeles County residents with physical or sensory disabilities found that 22% had difficulty accessing their health care provider's office; 31% of persons with severe disabilities reported such physical barriers (Center for Disease Control and Prevention, 2006).

Most findings relating to mammography and breast cancer care disparities come from large population-based surveys or cancer registry data, without sufficient detail to identify specific causes (Chan et al., 1999; Chevarley et al., 2006; Iezzoni et al., 2000; Iezzoni et al., 2001; Iezzoni et al., 2008; McCarthy, Ngo, Roetzheim, Chirikos, Li, Drews, & Iezzoni, 2006a; Wei et al., 2006). To explore how physical access affects breast cancer diagnosis and treatment experiences, we conducted in-depth, individual interviews with 20 women with chronic mobility impairments who developed early stage breast cancer. Although this study focuses specifically on breast cancer, we identify issues that all clinicians and health care facilities should consider more generally to improve physical access for their patients.

## Methods

### Conceptual Model

As our conceptual model, we used definitions from the *International Classification of Functioning, Disability and Health* (Table 1) (World Health Organization, 2001). Developed by the World Health Organization (WHO), this model introduces environmental factors as key determinants of disability. WHO groups assistive technologies, such as mobility aids, among environmental factors that facilitate participation in daily activities; barriers include impediments involving equipment and the built environment, among other factors. The Institute of Medicine recommended that this WHO framework guide U.S. data gathering initiatives involving functional status and disability (Institute of Medicine Committee on Disability in America, 2007).

## Study Participants

We recruited English-speaking women diagnosed with early stage breast cancer under age 60 years who had chronic difficulty walking or used wheeled mobility aids at the time of their breast cancer diagnosis. To avoid interference with active treatment concerns, we excluded women undergoing initial therapy. We identified potential participants by reviewing patient panels of breast cancer oncologists and through informal networks of women with disabilities (Kuzel, 1992). We did not review medical records, but instead relied on women to report that their cancers were early stage. Given our qualitative research methods and goals, we aimed to recruit 20 interviewees. We identified 22 candidates; 20 women completed their interviews. With these 20 participants, we achieved thematic saturation (i.e., later interviews added little new insight).

## Data Collection

We developed a semi-structured, open-ended interview guide using the WHO framework, published literature, and our previous research to suggest factors that could affect breast cancer diagnosis and treatment experiences of disabled women (Iezzoni, 2003; Iezzoni, 2003; Iezzoni & O'Day, 2006; Reis et al., 2004; U.S. Department of Health and Human Services, 2000). One researcher (L.I.I.) tested the draft guide during interviews with two women who met inclusion criteria (interviews excluded from analyses (Iezzoni, 2008)) and revised the protocol after reviewing findings with other investigators. The interview guide is available upon request.

One researcher (L.I.I.) made all contacts with participants and performed all interviews, either in person (Boston interviewees) or by telephone. Interviews occurred from December 2007 to October 2008; each took one to two hours. Given the topics, the interviewer informed participants that she uses a wheelchair (Brody, 1992; Krueger & Casey, 2000; Marshall & Rossman, 1995). Participants received a \$100 cash gift card.

## Analysis

Interview audiotapes were professionally transcribed. One researcher (L.I.I.) reviewed all 20 transcripts and sorted text segments into 30 broad topic areas for in-depth analysis (some segments went into more than one topic area). All investigators reviewed these sorted texts to identify common elements and basic themes. We reached consensus about these themes during team meetings.

Institutional review boards at Beth Israel Deaconess Medical Center (Boston) and Massachusetts General Hospital approved this study.

## Results

Table 2 shows demographic and other characteristics of the 20 participants. Participants reported physical access barriers across various settings where women received diagnostic testing and treatment. Table 3 summarizes these concerns, along with recommendations for potential remedies.

## Mammography

All participants had had mammography at some point. Screening mammograms detected the cancers of 10 participants. Four women reported having no physical problems and requiring no accommodations during mammograms.

Six women said that accommodations were essential to performing the test. Handle bars affixed to mammography machines were especially useful for positioning or providing

support and stability: one woman described “hanging onto the machine.” Another woman’s specialized breast care center had a chair designed specifically for positioning women with mobility disabilities during mammograms. Some women used their own mobility aids for accommodations. “I stand up and use one crutch and just lean,” said a woman disabled by polio, who ambulates with two forearm crutches. Wheeled mobility aids assisted other women, such as an interviewee with multiple sclerosis (MS) who remains seated throughout the test:

I use a scooter that has an electric seat that goes up and down. ... [Positioning myself] entails turning my seat so that I’m not sitting straight forward but off to the side on the scooter, and then pulling the scooter in so that it’s in close proximity [to the equipment].

Other women reported difficulties with mammography because of physical access barriers compounded by their underlying disabling conditions. A woman with rheumatoid arthritis could not grip the mammography handle bars because of arthritis in her hands; standing was extremely painful. Another woman, tetraplegic from childhood polio, has a tracheostomy that complicates positioning. Her husband had come into the mammography suite to assist in positioning her, but he can no longer do this because of his own health problems. One woman with cerebral palsy (CP) experiences uncontrollable movements, exacerbated by exhortations that she remain still. Another woman with CP said her mammography facility does not have equipment that lowers to wheelchair height.

Fortunately my [power] wheelchair rises up, but it’s still very awkward. .... I’m top heavy, so it’s already painful enough. They’re tugging and pulling and stretching and going through all these different ... [positions for various required views]. Come on, give me a break! Then they ask me, “Can you stand?” No, I can’t stand. So we’ll have to do this the best way we can.

As several interviewees noted, radiology technicians play critical roles. An interviewee with MS described back-and-forth discussions with the technician about how to best position her for mammograms: “The two of us – and it depends on the technician – really are pretty creative at getting the pictures.” The woman with CP and movement problems identified a radiology technician willing to work with her. To stop her movements, they tried mild sedation, ear phones, and soothing music, without success.

What was best is that somebody’s taking the picture, and the second person ... [is] pushing me, holding me in position. ... It all goes to show that you can have equipment that’s not very accessible, but if you’re working with a good technologist who’s creative, listens, is flexible, and will problem-solve, you’ll probably get a decent outcome.

Seemingly random, unanticipated events can cause discomfort and potential safety concerns. A manual wheelchair user with a spinal cord injury kept her sense of humor during one such occurrence.

My boob [breast] was already in the little squisher, and the lady [radiology technician] ... had to leave the room for a second. I can’t really tell where my feet are. I don’t have that spatial awareness. ... Somehow my foot ... must have spasmed or something, and it hit the controls. ... Suddenly my boob was going up in the air. Luckily she came back in time.

### Examining Tables

Women need complete physical examinations at multiple points over the course of diagnosing and treating their breast cancers. Few interviewees, however, saw physicians with tables that automatically lowered to wheelchair height for easy transfers. For most,

getting onto standard fixed height examining tables presented considerable challenges. In certain instances, physicians resorted to examining them while the women remained seated in their wheelchairs. This made women feel they were getting poor quality care. As a scooter user disabled by polio said:

Even when I go to my oncologist, he will say, “Oh, don't bother to get on the table. Just sit in the chair.” Well, I don't feel I can get an adequate breast exam ... from that particular doctor without being able to ... lay down.

One interviewee's breast surgeon, meeting her for the first time, said he would examine her in her wheelchair, but the woman insisted on being moved to an examining table for a complete evaluation: the surgeon “and this other person lifted me onto the table, but I had to ask to have the breast exam on the table.”

Interviewees discussed various strategies for getting onto fixed height examining tables. One woman with a spinal cord injury, who described herself as a “jock,” said that with minimal assistance from clinical staff she can lift herself onto these tables. Several other women dismissed as unhelpful step stools or the step built into fixed height tables. “They have a great, big, high step,” said a woman disabled by polio. The doctor says “just step on the step. I say I can't: I have no thigh muscle in either leg.” Another woman, paraplegic from childhood polio, used her arms to get onto examining tables.

I can't even use the little thing they pull out for you to step up on. No, no, no, that doesn't work for me. I have to go on the side ... in the middle of the table. I belly flop on the table and use my arms to pull me so my body is [lying across the table]. Then I take my arm and lift the leg with the brace ... up on the table and the other one will follow with my body as I try to turn over. Of course, everyone is scared to death that I'm going to fall off the other side. ... Mind you, I'm still on my stomach. Now I'm shifting so my head is going towards the top of the table. ... Now I'm lengthwise, but I'm on my stomach, so I've got to turn over.

Other women relied on personal assistance. An interviewee with spinal cord injury was lifted onto examining tables “by either a couple of nurses or some guys in the hallway.” A woman with MS would “usually just ask someone to lift my feet up and to stabilize whatever I'm transferring to if it doesn't look stable, but I do most of it on my own.” An interviewee with rheumatoid arthritis said, “I'm afraid of people grabbing me the wrong way. So I have to be careful, and I have to tell them how to handle me.” An interviewee with CP described her staff-assisted transfer onto the examining table as “very awkward and very hard. I had a couple of doctors and nurses. One nurse ... strained her back when she was trying to help me get up on the table. I really felt bad about that.”

Some interviewees used their scooters to get onto fixed height examining tables. One woman stood on the platform in front of her scooter's seat; her husband then assisted her onto the table. Another interviewee used the power seat, which moves up and down, to assist in her transfer. An interviewee with CP used a sophisticated power wheelchair that lifts, tilts back, and reclines, allowing her to be almost fully recumbent while in her wheelchair. She no longer tries to transfer to examining tables but instead feels she gets complete examinations while lying in her chair.

While a few interviewees reported visiting other physicians (e.g., gynecologists) who have adjustable height tables for easy transfers, only one interviewee described her breast cancer care center as having this type of equipment:

Like a dentist's chair, it has the arm rest that [flips] up so you can actually slip right into and sit in the chair, put your legs down, ... and then close the arm rest. Then the doctor can lean it back if they need to examine you flat ... It was very easy.

Positioning once on the table posed additional difficulties. “I just can't do certain things or lay a certain way,” said the woman with rheumatoid arthritis. “If it's a flat table, they always have to put something under my knees because I can't straighten them out. They're always wondering what to do with my arms because I can't get them out of the way easy enough.” Arm positioning during breast examinations was also a problem for one interviewee with CP who described a “range of motion problem. My muscles are tight. I can't really put my ... hands way over my head.”

### **Radiation Therapy**

Several women who received radiation therapy reported problems getting onto the table. One woman's husband lifted her onto the table for each of her 26 radiotherapy sessions. A woman with MS went to a facility where only one out of the four tables automatically moved up and down. Sometimes she arrived for her session, and the automatic table was unavailable: “They had so many patients going through there, [reserving the table] would've been a logistical nightmare for them. ... Also [the radiotherapy machines] kept breaking down.” Radiotherapy staff used Velcro® straps to keep an interviewee with CP securely on the table, but positioning her arm was problematic:

You had to keep your arm over your head, a position I couldn't maintain. I said, “I'm not going to be able to do this, ... we're going to have to do something.” They said, “What?” I said, “Tie it there, fix it, or brace it.” ... There are all kinds of positioning devices that they could've used – Velcro, Velcro strapping. But they did none of that. ... They ended up using masking tape every single time.

In contrast, a woman with spinal cord injury described very positive radiation therapy experiences because of proactive problem-solving by staff.

The way my back is, it's easier if I have a little foam rest under my knees. They did that. And because I don't rest good on a very cold flat surface, they put blankets on the table. ... And because I get cold all the time ... because I don't have good circulation, they warmed the blankets every time I went. So I had warm blankets.

### **Implications of Bladder Management**

None of the women complained about inaccessible restrooms, but bladder management raised other issues. Several women described needing bladder accommodations during chemotherapy. Because of her neurogenic bladder and difficulties walking to the bathroom, nurses periodically catheterized one woman with MS during her chemotherapy sessions, placing her in a single room in the outpatient unit for privacy during this procedure. A woman with polio expressed gratitude for being positioned close to the restroom during her outpatient chemotherapy sessions. A woman with CP intentionally dehydrated herself before chemotherapy visits to minimize her bathroom trips; however, this made inserting intravenous lines and drawing blood difficult. “So I started drinking a lot of water,” she said. “When I went to the bathroom, I would have a friend walk with me with the IV [intravenous] pole.”

### **Other Care Experiences**

Interviewees mentioned other physical access barriers. Inaccessible weight scales posed a critical problem, since chemotherapy dosages are often set according to patients' weights. Some women who cannot stand independently reported they had not been weighed in many years. To obtain her weight for determining chemotherapy dosages, the oncologist of a woman with spinal cord injury lifted and held her in his arms while standing on a scale.

The same woman, paraplegic from a spinal cord injury, could not get onto the table for an imaging study. “I got in a fight with one of the nurses,” the woman recounted, “when she said, ‘You can’t walk? You can’t stand up?’ No, I can’t. ‘Well, why didn’t you call us and tell us?’” When the technicians refused to transfer her, the woman’s oncologist came over to lift her onto the table. One woman’s husband donned the protective vest to shield him from radiation exposure as he assisted his tetraplegic wife during an imaging study.

Even getting into the practice office was sometimes challenging. “If you’re in a scooter, ... you can sit outside the door until somebody comes,” said a woman disabled by childhood polio, “or you have to bang, bang, bang until somebody opens it.” Another scooter said, “I would have to depend on my husband or the kindness of strangers just to hold doors.”

## Discussion

The 20 study participants with mobility impairments who had early-stage breast cancer reported substantial physical barriers to accessing care, starting with screening mammography and extending throughout the course of treatment and follow-up. Even simply getting into their clinician’s office – and onto examining tables for full physical evaluations – was sometimes difficult. According to the women, these barriers added to the stresses of undergoing treatment in what were already anxiety-laden circumstances. Fortunately, as suggested by Table 3, fairly straightforward solutions exist to eliminate these physical barriers, such as installing accessible equipment, making this equipment available when needed, and planning for additional staff involvement as appropriate.

Although we focused here on the specific clinical context of early-stage breast cancer, our findings have implications for settings of health care more broadly. Regardless of their underlying health conditions, most persons periodically require complete physical examinations, accurate weights, and occasional imaging studies. Therefore, considering the accessibility of routine settings, specialized imaging, and other services is important. Interestingly – and somewhat surprisingly – the women did not raise concerns about bathroom accessibility. At least for these 20 women, this suggests that bathrooms, which for so long had been inaccessible, have been renovated to improve access. Nonetheless, some women had difficulty getting through the clinic door.

Eventually, even in inaccessible settings, the women did get the services they required. But this generally required staff – physicians, nurses, and other practice personnel – lifting the patient. The women felt this put them at risk of being dropped or injured. This also put clinical staff at risk. Among various private industries, general medical and surgical hospitals had the largest number of nonfatal occupational injuries and illnesses in 2007 (253,000), with ambulatory health care facilities having the fourth highest number (130,200); this translates into 7.7% incidence for hospitals and 3.0% incidence for ambulatory care settings (United States Department of Labor Bureau of Labor Statistics, 2008). One woman felt badly that a nurse was injured while transferring her onto an examining table; nonetheless, she needed a complete physical examination. In this situation, accessible equipment, such as automatically adjustable examination tables or lift devices, would benefit both patients and nurses.

As do similar interview projects, this study has important limitations. Our sample of 20 women does not represent the general U.S. population. In particular, study participants were highly educated and many had polio. Several women disabled by polio suggested that numerous chest radiographs obtained during childhood polio treatments heightened their risks for subsequent breast cancer. The breast cancer treatment experiences of our study sample spanned several decades, raising questions about the current relevance of older

experiences. However, in discussing physical access topics, many women mentioned their present day experiences with follow-up or continuing care. None suggested that physical access barriers no longer exist.

With aging “baby boomers,” growing numbers of Americans are living with disabilities, with an estimated 11.3% of Americans age 45 to 64 years old reporting difficulty walking three city blocks (Center for Disease Control and Prevention, 2009; Center for Disease Control and Prevention, 2009). Thus, in coming years, large numbers of patients visiting health care facilities will have impaired mobility. Planning ahead to ensure that health care facilities are accessible will benefit not only patients but also clinical staff.

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**Table 1**

## World Health Organization Definition of Disability\*

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“Umbrella term for impairments, activity limitations or participation restrictions,” conceiving “a person’s functioning and disability ... as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors,” including the social, attitudinal, and physical environments and personal attributes

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\*From the *International Classification of Functioning, Disability and Health* approved by the World Health Organization in 2001

**Table 2**

## Characteristics of 20 Participants

Characteristic	Number
Recruitment source	
Physician panel	3
Social networks of women with disabilities	17
Age at time of breast cancer (age at time of interview)	
30-39 years	3 (0)
40-49 years	7 (1)
50-59 years	10 (11)
60-69 years	0 (5)
70 years and older	0 (3)
Year of breast cancer diagnosis	
Before 1980	2
1980-1989	3
1990-1999	6
2000-2006	9
Race	
White	17
Other <sup>a</sup>	3
Education	
High school only	2
Some college but no degree	2
College degree	8
Postgraduate education	8
Marital status	
Married or partnered	11
Divorced	3
Widowed	1
Never married	5
Geographic region <sup>b</sup>	
New England	6
Middle Atlantic	4
South	2
Midwest	3
West	5
Underlying disabling condition	
Polio, disabled in childhood or post-polio syndrome as adult	9
Spinal cord injury	3

Characteristic	Number
Cerebral palsy	3
Multiple sclerosis	2
Other <sup>c</sup>	3

<sup>a</sup>Two women were African American and one was Asian

<sup>b</sup>Interviewees came from nine states

<sup>c</sup>Rheumatoid arthritis, degenerative disk disease, and surgical complication in childhood

**Table 3**

## Access Barriers Encountered by Women with Mobility Impairments and Examples of Potential Solutions

<b>Concern</b>	<b>Potential Recommendation</b>
<b>Inaccessible Equipment</b>	
Inaccessible mammography equipment	Install accessible mammography equipment: machines that lower to wheelchair height or machines that accommodate special chairs for positioning
Inaccessible examining table	Install accessible examining table or equipment (e.g., Hoyer lift) to transfer patients onto examining table
Inaccessible radiation therapy equipment	Install accessible radiation therapy equipment or device (e.g., Hoyer lift) to transfer patients
Inaccessible weight scale	Install accessible weight scale or other equipment for weighing persons (e.g., Hoyer lift that measures weight)
<b>Other Access Difficulties</b>	
Difficulty positioning while standing	Eliminate need to stand by using specially designed mammography chairs
Difficulty positioning while lying down	Work with patient to ensure comfortable and appropriate positioning (e.g., put foam cushion under knees, use Velcro® straps to position arms)
Uncontrollable movements	Involve second mammography technician to assist in holding patient in position
Inaccessible office doors	Install automatic door openers on interior doors used frequently by patients
<b>Policies and Procedures</b>	
Facility has accessible equipment but it is not available when patient comes for appointment	Implement scheduling policies that ensure persons who need accessible equipment have priority use of that equipment; develop ways of identifying patients with accessibility needs
Restroom policies	Ensure that women with bladder management problems are positioned as close as possible to restrooms during long outpatient visits (e.g., chemotherapy sessions)
Staff injuries while transferring patients; days lost from work because of workplace injuries	Install equipment to assist in transferring patients; if not possible, train staff in safe transfer procedures and in working with patients to ensure safe transfers
Unanticipated and unsafe events occur while staff is not in room	Avoid leaving patient unattended or ensure emergency call button is both accessible and readily available